DOCUMENT RESUME

ED 178 988 CS 502 705

AUTHOR Cassata, Donald M.
TITLE Death and Dying: Communication Parameters and Perspectives.
PUB DATE Nov 79
NOTE 15p.: Paper presented at the Annual Meeting of the Speech Communication Association (65th, San Antonio, TX, November 10-13, 1979)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Communication (Thought Transfer); *Communication Skills; *Death; *Health Services; Nonverbal Communication; Verbal Communication

ABSTRACT

Communication specialists have contributions to make to the study of death education and to health professionals in caring for the terminally ill and their survivors. Communication specialists can assist with identifying the communication behaviors associated with "stigma" reactions to death by the patient, the family, and the helping professional; can point to the significance of the setting for dying; can help coordinate psychological resources for the patient by helping various levels of communication occur; can help develop communication skills related to verbal messages with the dying; can teach the significance and meaning of nonverbal communication; and can help interpret the value and ways of expressing emotions. (TJ)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED178988

U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

DEATH AND DYING: COMMUNICATION PARAMETERS AND PERSPECTIVES

BY

Donald M. Cassata, Ph.D.
Department of Family Medicine
University of North Carolina
School of Medicine
Trailer 15, 269H
Chapel Hill, N.C. 27514

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Donald M. Cassata

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

SPEECH COMMUNICATION ASSOCIATION
SAN ANTONIO, TEXAS

NOVEMBER, 1979

CS502705

During the past decade, there has been a rapid increase in the awareness and attitude toward death and dying in our society. The groundwork for dealing with this taboo topic was laid substantially through the efforts of Elisabeth Kubler-Ross. In her two early works, On Death and Dying (1969), and Questions and Answers on Death and Dying (1974), she enhanced openness and identified many of the communication difficulties surrounding death and dying situations. In addition to her efforts, other scholars such as Feifel (1959, 1977), Garfield (1978), Glaser and Strauss (1965, 1966), Hinton (1967), Shneidman (1973, 1976), and Weisman (1972) have significantly contributed to the literature.

To this author's knowledge, communication specialists have not contributed to the study of death education or the management process of terminally ill patients and/or their survivors. It is the thesis of this paper that communication specialists possess important knowledge and skills for enhancing the study of death education and for assisting health professionals in caring for the terminally ill and their survivors. The following list of communication parameters which were drawn from communication research, communication theory and small group studies, demonstrates the beneficial perspective of the communication specialist.

COMMUNICATION PARAMETERS

Stigma

Stigma is the invisable shield which surrounds a terminally ill person or a grief-stricken survivor. It creates what Erving Goffman (1959, 1963) terms a "spoiled identity" and modifies the "definition of

the situation" and the "presentation of self". The social interaction is greatly affected by the "stigma" of death. Much of the difficulty of interacting with a terminally ill or grief-stricken individual depends on the personal meaning given to the particular situation. If we are intimately or emotionally involved with the dying person we can be restricted by our own sense of loss and grief; if we are responsible for the care of the individual we may be faced with our own vulnerabilities as a helping professional. It is important to determine the definition or meaning of the situation from the patient, the patient's family and from the helping professionals. Communication specialists can assist with identifying the communication behaviors associated with "stigma" reactions.

Setting

The setting is somewhat akin to the last parameter in that the setting or environment can define the situation and give it special meaning. Today, the hospital is symbolic of emergencies, expensive technology, surgery, and a place to die as well. From an interaction perspective, the hospital is almost an impossible place for people to have discussion or be able to talk to one another. This is especially evident if one desires to discuss personal issues. There are very few places which are private or provide a comfortable setting for individuals or family members to converse. The recent development of the hospice movement within the United States does provide a setting which is conducive for interpersonal interaction to occur. Other settings as nursing homes, funeral parlors, emergency rooms - affects both the content

and quality of the interaction. In addition to the quality of interaction, settings such as a physician's office or clinic, hospital or church, also provide a basis for a therapeutic milieu.

Relationship

Much of the burden of maintaining a relationship with the terminally ill person has been with the physician. Patients depend upon the physician for the management of their care. This dependency is an outgrowth of the present health care delivery system within the United States. Through the efforts of nurses, allied health professionals, clerics and families themselves, the care of the patient is naturally enhanced. However, because the physician is the person primarily in control of the diagnosis and treatment regimen, the physician usually assumes the responsibility for coordinating the care. Part of the ethos associated with physicians in our society fosters a healing and therapeutic relationship. Within the death and dying context the physician as well as the health care team have an additional role to play in developing relationships with the bereaved members of the patient's family. This is still an area of need within the health system which is not being effectively met.

In developing a relationship with a terminally ill person, the major focus should be to "get to know the patient as a person", and to allow the person to express their feelings of fear, sadness, anger, loneliness, guilt, or joy at their own pace. This necessitates involvement and time from the helping professional. Tomm, et al (1976) identified four types of relationships which are based on a continuum of increasing communication exchange (see Figure 1):

1. No Disclosure: is found in the situation where the physician

has not informed the patient of the nature and severity of his/her illness. Such situations do occur, especially when the patient is quite young or very old.

2. Partial Disclosure: perhaps most common type of doctor-patient relationship. Here, the physician may reveal the technical diagnosis, but does not elaborate on the prognosis.

3. Unilateral Open Communication: physician includes an explanation of the extent of the illness and its expected complications. The patient's physical condition and his/her feelings are discussed openly.

4. Mutual Sharing: personal thoughts and feelings of both parties in the situation are made explicit. Traditional roles and barriers are dropped, leaving two persons to face one another as equals sharing a very meaningful experience.

They further state that mutually disclosing relationships are somewhat rare between physician and patient, but are common between family members during the dying process. Nurses and clerics can provide mutual sharing with the patient at this time. Physicians do not have to be the major resource of psychological support. However, someone has to coordinate these resources with the patient and family. Similarly, Glaser and Strauss (1965) describe the various types of awareness as closed awareness (the patient does not recognize that he or she is terminal), suspicion awareness (the patient suspects terminality and attempts to learn more, while staff attempt to keep the context closed), mutual pretense (both patient and staff know of the prognosis and can communicate openly in terms of the prognosis), and open awareness (all involved know and can discuss their awareness and feelings with each other).

Verbal Messages

There are a series of questions which arise when a terminal illness or death occurs: What do you say or tell? When do you tell? Who do you tell? How do you tell? Even one of our most famous cartoon characters, Charlie

Brown, asked himself a series of questions as he found himself in an emergency room: "I wonder if I'm dying...." "I wonder if they'd tell me if I were dying...." "Maybe I'm already dead...." "I wonder if they'd tell me...." (Schulz, 1979).

Until the beginning of the seventies, a majority of physicians were opposed to telling patients they had terminal illness. As stated previously, the openness and attitude toward death and dying situations has changed a great deal. However, medical practice has not kept pace with the changed attitude. Bowen (1976), a leading family therapist, posits:

> The poor communication between the physician and the patient, and between the physician and the family, and between the family and patient are still very much as they were before. The basic problem is an emotional one, and a change in rules does not automatically change the emotional reactivity. The physician can believe he gave factual information to the patient, but in the emotion of the moment, the abruptness and vagueness in the communication, and the emotional process in the patient, the patient failed to "hear". (p. 377)

Cicely Saunders (1969), a noted thanatologist, summed up the issue when she said, "The real question is not, 'What do you tell your patient?' but rather, 'What do you let your patients tell you?'".

From the patient's point of view, Kalish (1978) studied 434 persons comparing ethnic background and beliefs surrounding terminal illness. With an equal sample of Black, Japanese-American, Mexican-American and Anglos, and controlling for the age of the sample, he asked the following questions which you may ask of yourself:

1. Imagine that a friend of yours is dying of cancer. He/she is about your age. He/she will die soon. Should your friend be told?

2. Who should tell the patient?

From 55-70% mentioned the physician, 16-30% stated the family, and a small number referred to the clergy.

3. If you were dying, would you want to be told?

More than 70% said "yes" in each ethnic group with the exception of Mexican-Americans, who reported 60%.

In terms of specific communication skills which may be used in interacting with terminally ill persons or the bereaved, Rogers (1961) identified the characteristics of a helping relationship as being primarily empathy, congruence, and unconditional positive regard. Enelow and Swisher (1979) created an inverted pyramid to identify degrees of control and interviewing skills (see Figure 1.). He defined the six areas as follows:

Facilitation - Encouraging communication or further elaboration or words that do not specify the kind of information sought, e.g., "I see", "uh-huh", a head nod, etc. Demonstrates interest.

Silence - "Give the person the floor" by being silent and attentive.

Confrontation - Describes to the person something striking about his/her verbal or nonverbal behavior. It usually directs the person to something he/she may not be aware of, e.g., "You look sad". "You sound angry", etc.

Support - Communicates interest in a liking for, or understanding of the person or which promotes a feeling of security in the relationship, e.g., "I understand", "That must have been very upsetting".

Reassurance - Helps restore the person's sense of well-being, worthiness or confidence, e.g., "Everything will be alright", "I will be with you".

Direct Questions - Asks for specific information, e.g., "Do you have any fears about dying?".

Most health professionals, especially physicians, have not had any special training in the above skills. Communication specialists can play

an important role in the teaching of these skills. Furthermore, much research needs to be done on the outcomes of such training for the management of terminally ill persons.

Nonverbal Messages

The teaching of nonverbal communication which includes body language, proxemics, paralanguage, touching behavior, eye contact, etc. are significant elements for communicating with the terminally ill or bereaved person. It is primarily through nonverbal messages that affective responses are interpreted and communicated. Holding one's hand, wiping the perspiration from one's face, sitting at the bedside, listening to the reminiscing, showing empathy in our eyes, are vehicles for making contact with the terminally ill and the bereaved. These nonverbal messages which foster our personal involvement may also increase our personal satisfaction as a helping professional. They certainly provide a means for expressing our emotion and professional caring.

Some other nonverbal factors which especially communicate to the patient that something is seriously wrong are 1) vagueness surrounding diagnosis or prognosis; changes in activity, medical care routines, procedures; and avoidance of discussions of disease or patient feelings; discussions outside of patient's room; decrease in personal contact; avoidance of discussion of future, over reassuring attitudes; visits from religious professionals, etc.

Affective Behavior

Given that death and dying situations have an emotional impact on the individual and his/her family, the helping professional is also often

encompassed by similar emotions. The value and ways of expressing emotions needs to be encouraged and facilitated. Being conscious of each individual's different state of readiness and comfort, this may be sensitively facilitated through mutual trust and openness and within a support milieu. Oftentimes the family members have more of an emotional reaction than the terminally ill person. Proper support needs to be provided to the entire family system. As stated earlier, feelings such as fear, sadness, anger, loneliness, guilt, helplessness, are best recognized and responded to through nonverbal behaviors. Communication specialists can assist in teaching skills for recognizing and responding to affective behavior.

CONCLUSION

It was the purpose of this paper to identify selected communication parameters which communication specialists can integrate into the study of death education and for assisting health professionals in caring for the terminally ill and their survivors. As the basis for any helping relationship, these parameters penetrate the stigma of death and assist in the struggle against pain and fear, and of having to say goodbye. Perhaps we will never fully understand or know death or be able to fully overcome the loss of a person whom we love, but through the assistance of another, the living journey can be made a little easier. Hendin (1973) gives an example of this process:

> The bereaved can review the experiences shared with the deceased. Talking out the situation helps the individual experience his loss. At the same time it is possible for a friend or relative to encourage too much discussion. The bereaved may indicate that there has been enough talk for a time. If this happens, an understanding person should recognize that what the bereaved may really need is the comforting presence of someone who cares.

Besides the need for further empirical assessment of the communication parameters and perspectives presented in this paper, the following research questions may be useful in directing future communication studies:

1. What are the communication strategies for dealing with terminally ill people who are at different stages of the dying process?

2. How do the different types of diseases (cancers, heart diseases, pulmonary problems, kidney failure) affect, if any, the communication strategies for dealing with terminally ill people?

3. How does the different type of death such as sudden death, death at birth, at old age, tragic death, etc., affect, if any, the communication strategies for dealing with the survivors?

4. How are communication strategies affected by cross-cultural variables?

BIBLIOGRAPHY

Bowen, M. "Family Reaction to Death", in Philip J. Guerin, Jr. (Ed.) Family Therapy: Theory and Practice. New York: Gardner Press, 1976, pp. 335-348.

Enelow, A. & S. Swisher. Interviewing and Patient Care. 2nd Ed. New York: Oxford University Press, 1979.

Feifel, H. (Ed.) The Meaning of Death. New York: McGraw-Hill, 1959.

Feifel, H. (Ed.) The New Meanings of Death. New York: McGraw-Hill, 1959.

Garfield, C.A. (Ed.) Psychosocial Care of the Dying Patient. New York: McGraw-Hill, 1978.

Glaser, B.G. & A.L. Strauss. Awareness of Dying. Chicago: Aldine, 1965.

Glaser, B.G. & A.L. Strauss. Time for Dying. Chicago: Aldine, 1966.

Goffman, E. The Presentation of Self in Everyday Life. New York: Doubleday/Anchor, 1959.

Goffman, E. Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, N.J.: Prentice-Hall, 1963.

Hendin, D. Death as a Fact of Life. New York: W.W. Norton, 1973.

Hinton, J.M. Dying. Baltimore: Penguin Books, 1967.

Kalish, R. "A Little Myth is a Dangerous Thing: Research in the Service of the Dying" in C.A. Garfield (Ed.), Psychosocial Care of the Dying Patient. New York: McGraw-Hill, 1978, pp. 219-226.

Kubler-Ross, E. On Death and Dying. New York: MacMillan, 1969.

Rogers, C.R. On Becoming a Person. Boston: Houghton-Mifflin, 1961.

Saunders, C. The Management of Terminal Illness. London: Hosp. Med. Publ., 1967.

Schulz, C. "Peanuts". The Durham Sun, July 13, 1979.

Shneidman, E. (Ed.) Death: Current Perspectives. Palo Alto: Mayfield, 1976.

Shneidman, E. The Deaths of Man. Quadrangle/The New York Times Book Company, 1973.

Tomm, K., J. Williams, G. Matheson. "Understanding the Dying Process". Canadian Family Physician. 22, 1976, pp. 62-65.

Weisman, A.D. On Dying and Denying. New York: Behavioral Publications, 1972.

FIGURE 1.

RELATIONSHIP OF DEGREE OF DISCLOSURE AND INVOLVEMENT IN DEATH AND DYING INTERACTION (ADAPTED FROM TOMM, ET AL, 1976).

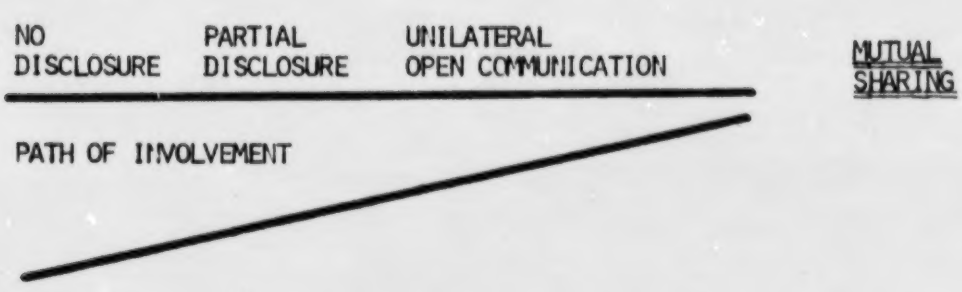

FIGURE 2.

INVERTED PYRAMID OF DEGREE OF CONTROL AND INTERVIEWING SKILLS (ADAPTED FROM EHELOW AND SWISHER, 1979).